

**GOVERNOR'S COMMISSION ON COMMUNITY-BASED ALTERNATIVES  
FOR INDIVIDUALS WITH DISABILITIES'  
HEALTH CARE COMMITTEE MEETING MINUTES  
November 18, 2016 – 10:00 AM  
Administration Building Felton-Farmington Room Dover, DE**

**PRESENT:** Eileen Sparling, CDS/UD Co-Chair; Helen Arthur, Delaware Healthcare Commission; Linda Barnett, League of Women Voters (phone); Louis Bartoshesky, Christiana Care/ DPH (phone); Linda Brittingham, CCHS (phone); Timothy Brooks, Parent; Alice Coleman, Smith-Coleman Counseling; Phyllis Guinivan, CDS; Michele Hamilton, DVI (phone); Jae Chul Lee, CDS (phone); Beth MacDonald, Office of Preparedness; Pat Maichle, DDC; Karen McGloughlin, DPH; Heidi Mizell, Autism Delaware; Terry Pepper, DSHS; Ann Phillips, Parent/DE-Family Voices (phone); Loretta Sarro, Delaware Office of Deaf and Hard of Hearing; Jo Singles, SCPD Support Staff; and Amber Rivard, Support Staff.

**Guest(s):** Brian Freedman, UD Center for Disabilities Studies

**CALL TO ORDER:**

Eileen called the meeting to order at 10:02 am.

**APPROVAL OF THE DRAFT MINUTES:**

Pat motioned for approval of the July minutes. Karen seconded the motion. The July 15, 2016 minutes were approved as submitted.

**ADDITIONS OR DELETIONS TO THE AGENDA**

None

**BUSINESS**

**New Autism and Developmental Disability Initiatives**

Brian spoke about three new projects at the Center for Disabilities Studies (CDS). There had been partnerships in developing these three projects such as Autism Delaware. Telehealth is a component to one of the projects. CDS received State and federal funding in the summer of 2016 for new initiatives that will infuse supports for individuals impacted by autism spectrum disorder (ASD) and other developmental disabilities.

Senate Bill 93 was passed and signed into law in the summer, and the Delaware Network for Excellence in Autism (DNEA) and the Interagency Committee on Autism (ICA) were created. ICA is an advisory body that works in identifying needs statewide and identifying evidence-based practices in support of individuals with autism and the family members. The ICA is made up of representatives from a variety of agencies and organizations statewide including people with autism and their family members. The ICA also provides advisement to the DNEA and guides the DNEA to focus on their community goals. DNEA will look at what training can be provided so the community understands autism in a more impactful way.

DNEA is a training and technical assistance entity that will provide training in various forms to agencies and organizations statewide that want to provide high quality support in services to

people and families with autism. Brian will send a list to Eileen from within the legislation recommendations from different legislators. He added the ICA has public meetings and they are always seeking more people to be involved. The funding for DNEA began November 18, 2016. CDS is preparing to hire DNEA staff along with a Director to oversee all the DNEA and ICA works to conducting a vision for fulfilling the strategic plan. Year 1 of funding will be identifying priorities for this year along with long-term priorities.

Senate Bill 92 was the sister bill to Senate Bill 93. It was designed to infuse significant resources directly into the school system to provide expansive training and technical assistance capacity for creating expertise across school districts statewide. The bill that passed for the DNEA infrastructure includes a contract and funding through the Department of Health and Social Services (DHSS) from Tobacco Funds. The goal is to embed those funds into the State Budget. Within the fiscal note of the bill, there is an expanded staff for Year 2. Year 1 focused on building infrastructure and hiring two training staff. DNEA received \$500,000 for Year 1 and \$800,000 for Year 2. ICA is concerned about funds deteriorating and are trying to secure funding with the new administration. The Division of Vocational Rehabilitation has members on the ICA with other agencies that assists adults with Division of Developmental Disabilities Services (DDDS) and the Division of Substance Abuse and Mental Health (DSAMH). A main area focused in the strategic plan is involving employment and adult services. Anyone from school districts to adults will be eligible for services from the DNEA when the funding and training have been processed.

The State Implementation Grant for Improving Services for Children and Youth with ASD is a federally funded grant that was received from the Maternal Child Health Bureau (MCHB) for the third project at CDS called, Building Bridges: Improving Access to Timely and Appropriate Access to Services for Children with ASD/DD (Autism Spectrum Disorder/Developmental Disabilities) and Their Families. This is a three-year grant and it is a part of the federal Autism Cares Act (ACA) that funds many autism-related initiatives throughout the US.

This project carries multiple goals such as the following:

- Improving care coordination for families of children at-risk or diagnosed with ASD.
- Improvement of screening routines for detecting children with ASD.
- Increase capacity by providing timely evaluations and diagnosis of ASD.
- Process of proceeding to Early Intervention services.
- Increasing utilization of telemedicine and telehealth strategies.
- Improving family skill, knowledge and self-efficacy through variety of supports.

Partners are Autism Delaware, Delaware Family Voices, Nemours, Child Development Watch (CDW) and Department of Education (DOE).

Strategies taken to ensure the goals for the grant include:

- Autism Care Team (ACT) will be a sub-section in Autism Delaware and it will provide family navigation and care coordination for families that receive medical examinations or screenings that will encourage them to pursue services related to autism. ACT will also provide support to doctor offices to connect families into the treatment and evaluation systems.
- Tele-TOTs (Treatment on Time) will encourage individuals in Sussex County to seek medical assistance and utilizes telemedicine/telehealth in providing evaluations,

diagnostic services, behavioral therapy and care coordination. Tele-TOTs will be supervised by Nemours.

- MCHAT-R (Modified Checklist of Autism in Toddler-Revised) strategy will be training pediatricians, family practice physicians and case managers in evaluating people suspected of autism. MCHAT-R will be led by CDS and DPH.
- Increase in capacity for evaluations with post-doctoral individuals at CDW North and South. Nemours and CDW will be overseeing this strategy.
- An increase in capacity to provide high quality EI services. There will be training for early intervention specialist and will be overseen by CDS, DOE and CDW.
- Parent-2-Parent program from Delaware Family Voices provides emotional and informational support to families.

Part of the grant will focus on the activities that are being developed to continue operation after the three-year funding is over. Karen asked if CDS had aligned their activities with health innovation strategic planning and priorities. Brian commented that CDS has been in contact with the health innovation staff. He added this project launched in September 2016. Someone asked if CDS is processing other forms of screening for people with suspected developmental disabilities other than MCHAT-R. Brian stated that CDS will start with using the MCHAT-R to identify autism and will process those goals first before starting with assistance for identify other disabilities. The ACT Family Council will connect with all entities that are providing assistance with this project.

The LEND (Leadership Education in Neurodevelopmental Disabilities) Program is the final funded project for CDS. LEND is a national network of training programs for graduate students and post-doctoral professionals in early career professionals to be provided with interdisciplinary multi-cultural centered evidence-based skills. The main focus of the LEND Program is to infuse expertise for an extended period of time within the state. It is federally-funded for five years and continued funding is available in five-year cycles. There are 13 core disciplines that LEND programs will be funding. LEND Programs have gained trainees who are family members and trainees from the fields of physical therapy, special education, speech language pathology, nutrition and clinical psychology. CDS finds trainees by reaching out to the graduate programs of clinical psychology or other related fields in those disciplines. There will be a core faculty mentor for each disciplinary training involved in the program. CDS is working with training programs for donating more for funds or identify other places to find funding to increase the number of trainees and more disciplines. Eileen asked if the trainees are located from University of Delaware (UD) or other graduate programs nearby. Brian stated the trainees in physical education, speech language pathology and nutrition are from UD and clinical trainees are from Nemours/A.I. duPont Hospital post-doctoral training program. There are also graduate training programs including Delaware State University (DSU) social worker training program that CDS would want to include in their LEND program as another discipline. There will be financial support to the trainees participating in the LEND program and it is undecided how many trainees in total there will be during the five-year funding cycle.

LEND is an intensive one-year training curriculum with content in each of these areas:

- Leadership Development
- Learning interdisciplinary practice and discussions in activities.

- Family mentoring experience- identifying family members in the community and trainees spending time with those families. A suggestion was made to include single-parent families to become more diverse in different types of families with their needs and struggles of everyday life.
- Community/clinical observations
- Capstone project
- Guidance from core faculty mentor

### **DHSS Inclusion Policy Implementation**

Eileen spoke about not receiving CDC grant funding. DHSS has provided an extension until March 30, 2017 to focus on the implementation of the Inclusion Policy.

Secretary Landgraf saw the importance of the policy from an impact perspective. The policy has the potential of placing people with disabilities on the radar to vendors and contractors that could provide services. There are other elements to the policy, but CDS will focus on the contracting portion of the policy only. The Committee will have tools that will embed the language about disability, accessibility and inclusion into RFPs and translated into the proposals that submitted. In order to move forward, CDS developed an online training located on the Delaware Learning Center for State employees. The online training is titled “Creating Inclusive Programs.” The online training is 20 minutes and will have an overview of disabilities, accessibility, and when a new program is created, a focus on how to make it inclusive. It has not been discussed if this training will be mandatory to all State employees. Secretary Landgraf had discussed the intent to expanding this training to other Departments when the training is successful within DHSS. To successfully include the Inclusion Policy in DHSS programs and the training, there will be web-based tools to provide assistance to State employees that will attend the online training.

There is a Technical Assistance (TA) portion being created by Eileen and CDS to move the Inclusion Policy forward by discovering what tools are needed for TA.

### **Transition / Health Equity Plan Implementation**

The Health Equity Plan has not progressed with the workgroups. There is a shortage of staffing for the workgroups. The Committee discussed how to move the Health Equity Plan (HEP) forward.

The Committee discussed that some of the partners involved in the Health Equity Plan are discovering ways of how to progress forward:

- ***Improving Access to Care***-There was discussion with the staff at DCHI (Delaware Center for Health Innovation) about the curriculum they are developing for the workforce and creating a module around people with disabilities. The curriculum will be due February 2017.
- ***Inclusive Health Promotion*** - CDS had done a pilot for health promotion with DDDS, using the Health Matters curriculum. The participants in the Day Program at Fox Run had a positive experience with this promotion but staff suggested modifications on how to staff and promote the program in the future. The program was a 12-week program that consisted of health nutrition and physical activity. Jill Rogers had discussed staffing for manager positions to add to health promotion into those job positions. Karen asked about the possibility of CDS creating training centered on promoting health similar to what they

implement for Inclusion Policy. She added that understanding the importance of inclusive health is a barrier that needs to be overcome with finding the connection between people with different developmental disabilities and the employed individuals that focus on assisting people with disabilities. Eileen agreed with the training being a critical piece to promoting inclusive health.

Tim Brooks spoke about an issue in the Health Equity Plan that DDDS had decided to outsource nursing. There is a disconnection between DDDS and the outsource providers. He added that if Jill Rogers is promoting inclusive health, outsourcing nursing services could be an opportunity to integrate health, nutrition and diet issues concerning the families in the community. Eileen commented another issue in the Health Equity Plan relates to ELPs (Essential Lifestyle Plan) and trying to integrate its health promotion of physical activity to reflect what the Committee wants to provide.

Updates in the workgroups in 2016:

***Emergency Preparedness*** - Eileen stated in her meeting with Tim Cooper regarding emergency preparedness, DDDS should consider personal planning that a community agency could be responsible in assisting a contractor to develop a personal emergency plan for their clients. The Preparedness Buddy pamphlet is a simple version of an emergency plan that is distributed to the community to be prepared in an emergency. In the pamphlet there is a checklist of necessary items that the individual can write down such as what are their allergies, medication they need, who is their primary care doctor, what is needed for their service animal or pet and many other important information to know. There was discussion that having the pamphlet being handed out to the community is not enough. There should be a discussion of how to distribute these Preparedness Buddy pamphlet including one-on-one conversations with the individual, having family members prepare their emergency plan together or outsource resources assisting the individuals. They also have been working with People with Access and Functional Medical Needs Group and have made some progress in putting all of the information into a contract to promote health.

***Data Monitoring & Surveillance*** - Tabitha Offut-Powell had updated the Committee on the progress of this workgroup late last year. The update consisted of the survey they created with Public Health (PH) and examined the data that was collected from it. The staff was conducting interviews to discover in more detail what disability status indicators are being collected and what systems are used to have an understanding of information on the potential of the data and how to use it.

The Committee prioritized what the focus would be in January 2017. The main priorities were:

- Keeping the Inclusion Policy progressing.
- Maintain a Committee structure and a group effort around the Health Equity Plan objectives.
- Identifying and developing plans to progress forward with the plan and policy.

#### ***Delaware Center for Health Innovation***

There was an update on the Delaware Center for Health Innovation (DCHI). Phyllis provided an update on recent DCHI meetings. The Patient and Consumer Engagement Committee recently held numerous public forums statewide. The Healthy Neighborhoods workgroup has been developing goals for a program into different areas in Claymont and Sussex. Peggy Geisler, head of the Sussex Health Coalition, developed a template on priorities that DCHI wants for their

Healthy Neighborhoods program. There are two websites that provide more insight into the programs that are in development: [www.dehealthinnovations.org](http://www.dehealthinnovations.org) (DCHI website) and [www.choosehealthde.com](http://www.choosehealthde.com). The Workforce Committee is working with the University of Delaware (UD) to develop a curriculum with modules that require an on-site team portion for completing the curriculum. One potential module would focus on disability.

Ann spoke about the concerns of care coordination and the lack of focus on children. Children have different needs for healthcare coordination versus adults. This should have a better understanding of the differences and what is needed for both.

### ***Transition***

Eileen stated that there are issues with the transition to the new administration in both federal and State funding. There was discussion with others involved in Health Equity Plan and they are concerned with how to plan for 2017 funding. Three questions asked were:

1. What can the Committee provide in terms of informing the new administration within the state?
2. What are suggestions for how the Committee can make progress in the objectives? Options for funding in 2017?
3. What are the opinions of the Committee about the workgroup structure and how to have the Health Equity Plan progressing forward with limited staff support?

Karen suggested finding an organization or agency to commit including the Health Equity Plan into one of their workgroups. Eileen stated about the Emergency Preparedness CDC Grant in Public Health provided objectives around people with access and functional needs. When the grant funding for the Health Equity Plan was lost, another group had adopted the plan with the objectives and their work has been progressing. The Committee still needs to find other workgroups for Access to Healthcare and Inclusive Health Promotion, and the Data and Surveillance. Tim commented that he mentioned to the DDDS Council about health-based issues and DDDS had shown interest in working with the Committee to solve the issues. Eileen stated that she will have a follow-up with Jill Rogers to discuss the health-based issues. A Committee member stated about Access to Healthcare is not limited to accessing state services, but having access to general health services statewide. A suggestion was made about seeking funding for the grant outside of government funding such as a hospital. There was discussion about making the new administration aware. Eileen stated that she, Beth MacDonald, and Tim Brooks were discussing about writing a Progress Report for the Health Equity Plan to present to the new DHSS administration. Tim agreed that presenting it to the Secretary would be a key factor to moving forward with the plan. A suggestion was made for the Committee to create a list of who to send their Progress Report Update to the new administration.

### **ANNOUNCEMENTS**

Jo will send out the 2017 meeting schedule. The meetings will remain on the third Friday of the month, 10 a.m. -12 p.m. and is securing locations. The locations will alternate between a new location in Dover and CDS.

### **Partner Updates**

The LIFE Conference will be held January 25, 2017 at Dover Downs. Registration will be online on [www.lifeconference.org](http://www.lifeconference.org). There is money set aside every year for families that would like to

attend the conference, but cannot afford it. A few families have registered and paid by DE-Family Voices. A suggestion was made for the Planning Committee to provide outreach to communities.

A new website called <http://www.preparede.org/> has been developed by Delaware Citizens Corp, Delaware Division of Public Health, DEMA and Delaware Medical Reserves. The Preparedness Buddy brochure is on the website.

Karen had attended a Human Trafficking Council Conference about sexual exploitation and human trafficking in Delaware. It has become a major concern all over the East Coast. Those at highest risk are run-away children and children exploited through the internet. There is not much collected data on human trafficking and the Council is trying to find more connections with children with disabilities to raise awareness statewide.

Eileen has been partnering with Professional Studies at UD in developing a certificate program around cultural competency and health care. It will be offered in spring 2017, will be a ten-week program and will be focused on competency around working with diverse populations (race, ethnicity, LGBT, disability, religion, etc.).

## **ADJOURNMENT**

The meeting adjourned at 12:01 pm.

Respectively submitted,

Amber Rivard  
Administrative Specialist

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